

March 2024

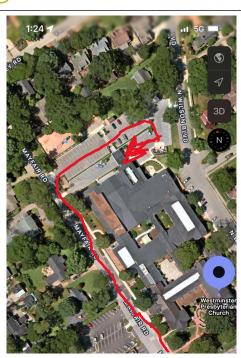
NCA Tennessee (NCAT) -- serving those living gluten-free in Middle Tennessee

# Join Us on Saturday, March 16<sup>th</sup> for a discussion of ideas of how we can talk to those we meet who have been newly diagnosed with CeD

Some of our members have shared that they meet people at the grocery or in their other community groups who share that they have either been newly diagnosed with CeD, or that they think that they may have some of the symptoms of CeD. We have decided that the program for our March meeting should help us learn how to talk to those people we meet who need information about CeD.

We first thought of getting someone from the Vanderbilt University Medical Center's Celiac Disease Center to provide a program for this meeting. Spring break is taking them away that Saturday, so they provided some basic information and suggestions for us to consider and discuss at our meeting on March 16, 12:30 – 2:30 pm. Please come with your experiences and your questions so that you can become better prepared to handle these situations in the future.

We will be meeting in a new room within **Westminster Presbyterian** from now on. Turn on Mayfair off West End Ave. as before, but continue past the west entrance to the back parking lot and enter at the **North Entrance**. Go in at the portico, take the elevator to the second floor and enter the **Overlook Room**, across from the elevator.



## Valerie Kraft, a former member of NCAT while she was at Vanderbilt, now works for Beyond Celiac. We have asked her to introduce this organization to us.

How time flies!! It seems like only yesterday I was meeting with Carol Ann and Jack for the first time as a prospective Vanderbilt student. I'm thrilled to currently be working at Beyond Celiac as their Director of Community Engagement, continuing my work in the celiac disease community and working to ensure a future where we can all eat without fear!

Originally founded as the National Foundation for Celiac Awareness in 2003, Beyond Celiac is the leading patient advocacy and research-driven celiac disease organization working to drive diagnosis, advance research and accelerate the discovery of new treatments and a cure. Together with my team, we work to advance widespread understanding of celiac disease as a serious genetic autoimmune condition and work to secure early diagnosis and effective management. We empower our community to live life to the fullest, and serve as a leading and trusted resource that inspires hope, accelerates innovation and forges pathways to a cure.

As the Director of Community Engagement, my role is to serve as the connection between the organization and the community and to oversee all of our community programs and events! This includes events like our <a href="Step Beyond Celiac 5K">Step Beyond Celiac 5K</a> series - which has now expanded to three in-person races, plus a virtual race each year! - our <a href="Evening Beyond Celiac">Evening Beyond Celiac</a> event, and our biennial Community Summit. I also have the opportunity to work hand-in-hand with our ambassadors, volunteers, and interns to help expand national and international awareness of celiac disease, drive funds towards critical research, and create meaningful opportunities for engagement.

It's been an absolute honor and joy to be a part of the Beyond Celiac team, and I invite all of you to connect and engage with us! With a variety of opportunities, there's something for everyone:

- -Share your story through our <u>Voices of Celiac</u> story collection, or help advance research by completing surveys in our <u>Go Beyond</u> Celiac research database.
- -Join our virtual Step Beyond Celiac 5K during Celiac Awareness Month. Registration opens March 1st!
- -Connect with us on Facebook, Instagram, or TikTok
- -Become a Beyond Celiac volunteer or ambassador
- -Host a fundraising or awareness event
- -Sign up for our <u>research newsletter</u> to learn about the latest advancements

And, of course, you can always reach out to me directly to learn more about any of our programs! I am here to help however I can :)

I hope everyone has a wonderful start to your spring!

Sincerely,

Valerie Kraft vkraft@beyondceliac.org





# Another NCA program is

Could YOU volunteer to meet with Second Harvest to begin discussions about adding gluten free foods? We could certainly use help from some of our members to work with Second Harvest to advise them on the needs for gluten free foods and to coordinate with NCA to have food suppliers contribute products to be distributed.

# Actively Support Legislation that will help people living gluten-free

#### 1. Support the ADINA Act to label gluten in medication

On June 21, 2023, Representatives Mike Gallagher (R-WI), Dean Phillips (D-MN), Mike Lawler (R-NY), and Mike Sherrill (D-NJ) introduced the bipartisan **Allergen Disclosure In Non-Food Articles (ADINA) Act**. Senator Richard Blumenthal (CT) introduced a companion in the Senate.

H.R.4263 and S.2079 - The Allergen Disclosure In Non-Food Articles (ADINA) Act; To amend the Federal Food, Drug, and Cosmetic Act to require the label of a drug intended for human use to identify each ingredient in such drug that is, or is derived directly or indirectly from, a major food allergen or a gluten-containing grain, and for other purposes.

Support this Bill by calling or writing to your local representatives and asking them to sign on to support it. Feel free to <u>edit this letter</u> and send it to your representative.

Click here to <u>find your representative</u>. Click here to <u>read the press release</u> and visit congress.gov for detailed information, including a list of the current co-sponsors in the <u>Senate</u> and <u>House of Representatives</u>.

#### 2. Support the Food Labeling Modernization Act to label gluten in food

The Food Labeling Modernization Act (FLMA) of 2023 was introduced on April 26, 2023 by House Energy and Commerce Committee Ranking Member Frank Pallone, Jr. (D-NJ) and Senator Richard Blumenthal (D-CT). Read the press release here.

- Click here to view H.R. 2901.
- Click here to view S. 1289.

Pertinent to the gluten-free community, the FLMA would amend the Food Allergen Labeling and Consumer Protection Act (FALCPA) to require that food product packaging disclose ALL gluten-containing grains (wheat, barley, and rye) in the ingredient list and/or "Contains" statement on ingredient labels.

<u>Sign on to this very important piece of legislation!</u> Use your voice TODAY to protect people with celiac disease and gluten-related disorders.

Proposed Labels: Natural Flavors (Barley); Yeast Extract (Barley), and Malt Syrup (Barley).

#### 3. Support the Medical Nutrition Therapy Act of 2023

On November 14, 2023, Representative Robin L. Kelly (D-IL) and Representative Jennifer A. Kiggans (R-VA) introduced the Medical Nutrition Therapy Act of 2023 to the House, while Senator Susan Collins (R-ME) and Senator Gary Peters (D-MI) introduced it to the Senate.

Under the proposed bill, coverage for medical nutrition therapy would be expanded under Medicare Part B to cover people with gastrointestinal diseases, including celiac disease as well as other conditions.

Click here to read the House Bill, or Click here to read the Senate Bill.

Read the statement from the Academy of Nutrition and Dietetics urging Congress to pass these bills.

Write, call or email your Congressional leaders to co-sponsor and support the passage of this important Bill.

Click here to find and contact your Representatives and ask them to support the Medical Nutrition Therapy Act of 2023.

Click here to contact your Senators and ask them to support the Medical Nutrition Therapy Act of 2023.

#### 4. Support the citizen petition to label gluten

Make your voice heard; support 10-year-old Jax's citizen petition to require the labeling of gluten on all food products. This <u>Citizen Petition</u> is a response to President Biden's nationwide call-to-action with the "White House Challenge to End Hunger and Build Healthy Communities."

Read more about Jax's petition here.

Click on the FDA-2023-P-3942 Docket to submit your comments to the FDA website.

#### 5. Ask Your Members of Congress to Join the Celiac Disease Caucus

Representative Betty McCollum officially launched the bipartisan House **Celiac Disease Caucus** by circulating a Dear Colleague letter requesting House members to join.

Rep. McCollum has celiac disease and has been a driving force in compelling the NIH to fund celiac disease research for the past two years.

The strength of this Caucus will be instrumental in securing NIH funding and legislation to improve the quality of life of those with celiac disease.

We urge you to ask your Members of Congress to add their names to the growing list of Celiac Disease Caucus members. Feel free to use any portion of this letter (click here to download the letter) in your message to your Members of Congress. Click below for an easy way to contact your local Members of Congress. Please contact Pat Maillet at <a href="mailto:patrick.maillet@mail.house.gov">patrick.maillet@mail.house.gov</a> with Rep. Betty McCollum's office with any questions about the Celiac Disease Caucus.

### Upcoming Events for NCAT—

May 18<sup>th</sup> – Picnic – Location Ideas Wanted!!
May 13-19 -- Celiac Awareness Week
Watch for a Summer Cookout!
September 21<sup>th</sup> Meeting
Holiday Potluck on November 15<sup>th</sup>!

We were too late to book the picnic pavilion in Brentwood this year. So, please let us know about other picnic shelters where we can book our May 18<sup>th</sup> picnic!!

We have set a date for the September meeting, but we need some ideas for a program. What would you like to hear about or learn from this program? Give us your ideas. We'll find a speaker.

**Put November 15th on your calendar now** so you won't miss our annual **Holiday Potluck**, always the best attended and most delicious meeting of the year! We will let you know the details in future newsletters.

#### In Memoriam of Sister Angelina, a long-time member of our Celiac support group.

Sister Angelina Langston, O.P., a member of the Dominican Sisters of St. Cecilia Congregation in Nashville for 71 years, died February 15, 2024, She was 89 years old. She was born in Paducah, Kentucky, the daughter of Paul Vernon and Lena Mae Langston. She graduated from Saint Thomas Academy in Memphis in 1952 and entered Dominican Sisters in August of the same year, making profession of vows in 1954. Sister Angelina served for over 50 years as a teacher in Catholic schools in Tennessee, Virginia, and Alabama.

We recall her coming for meetings mostly when we were at Centennial. She loved to attend the potlucks and she always brought a dish made by the convent's kitchen staff. She often brought a couple of young nuns with her who also were gluten-free.

Tori Ross recalls that Sister Angelina exuded a cheerful and positive warmth. She graciously accepted invitations to say the blessing before our Thanksgiving potlucks, when she was able to join us. The past few years, she has not been able to join us, but even though she was in the nursing facility at the convent, she continued to care for others there who needed her care.

